MINNESOTA
MDH
DEPARTMENT OF HEALTH

Protecting, maintaining and improving the health of all Minnesotans

December 15, 2008

Nathan M. Hansen
Attorney at Law
2440 North Charles Street, Suite 224
North St. Paul, MN 55109

Re: Data Practices Requests

Dear Mr. Hansen:

This letter responds to your letter dated November 18, 2008, inquiring about the status of your data practices requests and making a further data practices request.

You first asked about the documents you inspected of which you had requested copies. For the documents of which you requested hard copies, we are sending the copies within a week under separate cover, as well as an invoice for the copying costs. For the documents for which you requested copies in electronic format, we will provide these to you within a week via e-mail attachments at no additional charge.

You then stated that the documents assembled "did not entirely encompass" your original request. In your original request of July 28, 2008, you asked for "Documents, correspondence, contracts and the like relating to the release of newborn blood spots to the University of Minnesota, the Mayo Clinic, or any other organization, individual, or entity for the purposes of research or any other purpose." Your letter of October 24, 2008, reiterated this statement and then stated, "I am aware that people or entities have made applications for and have received dried blood spots for research. It is my understanding that these requests for samples for research are handled by an institutional review board. It is these documents that I was requesting in my original request."

Your July 28 request specifically referred to documents relating to the "release" of newborn bloodspots and listed organizations which are external to the Minnesota Department of Health (MDH). The documents that were gathered for your inspection were those related to the use of bloodspot samples by external parties pursuant to the MDH contracts identified in response to your request. The MDH Institutional Review Board (MDH IRB) has been established to review proposals for MDH-sponsored research. Outside entities such as the University of Minnesota and the Mayo Clinic have established their own IRBs that review proposals for the projects sponsored by these outside entities. If MDH jointly sponsored a project with the outside entity or conducted the project itself, the MDH IRB has records related to the project. There would, however, not necessarily be "a release" of bloodspot samples to an outside party to conduct these projects. We are therefore treating your October 24, 2008, letter as a new request. MDH IRB staff, in conjunction with MDH Public Health Lab staff, are determining which MDH IRB documents are related to MDH-sponsored projects using the newborn bloodspots. Projects that were entirely sponsored by an outside entity would go through that entity's own IRB, not the

MDH IRB, and MDH would not have records of the outside IRB review, other than those maintained by the MDH Public Health Lab which were in the collection of documents you inspected.

In your letter of November 18, you made a new request for "a copy of the written parental informed consent form currently in use by the Department for the collection of newborn bloodspots." Newborn bloodspots are collected pursuant to state law, Minnesota Statutes sections 144.125 to 144.128, which requires the testing to take place. No "written parental informed consent" is required and MDH does not use such a form. Rather, the law requires that parents be informed of and have the options to decline the testing or to have the testing but have the results and/or blood samples destroyed. Enclosed is a copy of the brochure which is one of the means by which parents are informed of their options, as well as copies of the standard forms for parents to sign and submit in order to refuse newborn screening or to direct the department to destroy the test results and/or the blood samples. Copies of these same standard forms were previously provided to you in response to your first data practices request as of September 23. Also enclosed is the form entitled "Instructions for Birth Facilities Regarding Parental Newborn Screening Options," which is a checklist of MDH's instructions for healthcare providers for informing parents about newborn screening.

Additionally, your November 18 letter stated you had requested communications and notes related to MDH's 2008 legislative proposal regarding newborn screening. You stated that you do not believe there is any valid legal reason as to why certain documents related to the 2008 legislative proposal would not be provided to you in light of the conclusion of the 2008 session. As you were previously informed, we withheld certain documents pursuant to the Minnesota Statutes section 13.605. We have provided you access to all communications and notes requested, except as such documents constitute protected nonpublic legislative data maintained by the state administration as set out in section 13.605. The conclusion of the 2008 legislative session has no impact on the statutory classification of the documents as not public.

MDH staff are diligently proceeding with locating, retrieving, and assembling the copies and documents related to your various requests. If you have any further questions regarding the status of your several requests, please feel free to contact MDH Data Practices Coordinator Lynn Belgea at 651-201-5741.

Sincerely,

Sanne Magnan, M.D., Ph.D
Commissioner
P.O. Box 64975
St. Paul, Minnesota 55164-0975

Encl.